



Review

Barriers to quality health care for the transgender population



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ABSTRACT

The transgender community is arguably the most marginalized and underserved population in medicine. A special issue focusing on men's health would be incomplete without mention of this vulnerable population, which includes those transitioning to and from the male gender. Transgender patients face many barriers in their access to healthcare including historical stigmatization, both structural and financial barriers, and even a lack of healthcare provider experience in treating this unique population. Historical stigmatization fosters a reluctance to disclose gender identity, which can have dire consequences for long-term outcomes due to a lack of appropriate medical history including transition-related care. Even if a patient is willing to disclose their gender identity and transition history, structural barriers in current healthcare settings lack the mechanisms necessary to collect and track this information. Moreover, healthcare providers acknowledge that information is lacking regarding the unique needs and long-term outcomes for transgender patients, which contributes to the inability to provide appropriate care. All of these barriers must be recognized and addressed in order to elevate the quality of healthcare delivered to the transgender community to a level commensurate with the general population. Overcoming these barriers will require redefinition of our current system such that the care a patient receives is not exclusively linked to their sex but also considers gender identity.

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Introduction

Over the past decade the visibility of the transgender (trans) community has been steadily increasing due, at least in part, to representation in pop culture and the media. Nonetheless, while public awareness of trans

issues has been heightened, clinicians, public health researchers, and officials are becoming increasingly aware that trans persons represent one of the most marginalized and underserved populations in medicine. In fact, both the trans community and healthcare providers agree that there are many barriers to healthcare for trans persons that cluster around four main issues: (1) reluctance to disclose, (2) lack of provider experience and resources, (3) structural barriers, and (4) financial barriers [1,2]. This review will focus on these critical issues that create most barriers to care for trans patients as well as potential ways in which they can be addressed. Unfortunately, trans persons are frequently reluctant to disclose gender identity even when receiving medical care because of social stigma and cultural prejudices. While we can be optimistic that such prejudices no longer plague the medical profession,

Abbreviations: APA, American Psychological Association; HT, cross-sex hormone therapy; DSM-5, Diagnostic and Statistical Manual of Mental Disorders 5th edition; EHR, electronic health record; FTM, female-to-male; LIS, laboratory information system; MTF, male-to-female; trans, transgender; WPATH, World Professional Association for Transgender Health.

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the level of proficiency of health care providers in caring for trans patients is very limited [2]. Similar to lesbian and gay populations, trans patients have unique healthcare issues and needs that are often not recognized and a lack of education, training, and resources for providers compounds the problem [3–6]. Lastly, even when gender identity is disclosed to a well-versed and caring provider both financial and structural barriers still exist [7]. It is important that the quality of healthcare delivered to this very vulnerable population is discussed openly so that solutions that can elevate it to equality with other populations can be identified.

It is important to understand that the terms “sex” and “gender”, while often used interchangeably, have specific medical and psychological meanings. “Sex” commonly refers to physical characteristics whereas “gender” represents identity and self-image [8,9]. Trans persons experience their gender as being different from the sex that was assigned to them at birth, otherwise referred to as gender nonconformity [1]. Gender dysphoria refers to the distress that can arise from gender nonconformity [10,11]. For some, gender dysphoria may meet criteria for a formal diagnosis that might be classified as a mental disorder. In the DSM-5 these criteria include a strong desire to be treated and identified as the expressed gender, which results in an increased risk of distress leading to significant social and/or occupational impairment [12].

Formal epidemiological studies on the incidence and prevalence of gender nonconformity have not been conducted due to the enormous difficulty of achieving realistic estimates. Over the last several decades, studies from numerous countries have published prevalence data ranging from 1:11,900 to 1:45,000 for male-to-female (MTF) trans persons and 1:30,400 to 1:200,000 for female-to-male (FTM) trans persons [8]. However, these numbers should be considered minimum estimates at best as they are derived from clinics where patients met criteria for severe gender dysphoria and had access to care.

The World Professional Association for Transgender Health (WPATH), an international multi-disciplinary professional association that publishes standards for the care of trans and gender nonconforming persons, released a statement in May 2010 urging the de-psychopathologization of gender nonconformity. The statement noted that “the expression of gender characteristics, including identities, that are not stereotypically associated with one’s assigned sex at birth is a common and culturally diverse human phenomenon [that] should not be judged as inherently pathological or negative” [8]. Thus, trans and gender-nonconforming individuals are not inherently disordered; rather, it is the distress of gender dysphoria that might be diagnosable and treatable. This theme was continued in the DSM-5 where gender dysphoria has now its own chapter, separate from sexual dysfunctions [12]. A separate chapter for gender dysphoria is more consistent with familiar clinical sexology terminology and removes the connotation that the patient is “disordered” [12]. In implementing this change, the APA and the DSM-5 affirmed that persons experiencing gender dysphoria need a diagnostic term that removes stigma, won’t be used against them in social, occupational, or legal areas, and protects their access to care.

Barriers to care

Reluctance to disclose

The existence of a diagnosis for gender dysphoria often facilitates access to health care and can guide further research into effective treatments. Treatment for gender dysphoria has become more individualized and may or may not involve a change in gender expression or body modifications [13]. The first step in treatment for gender dysphoria is a mental health screening or assessment, which is required to obtain referrals for HT as well as surgery if desired [9]. While not a requirement, psychotherapy is recommended by both The Endocrine Society and WPATH [8,14]. Collaboration between mental health professionals and providers in other health disciplines (e.g. primary care, endocrinology, and surgery) is critical for appropriate patient management. Medical treatment options

include feminization or masculinization of the body through HT and/or surgery and are medically necessary for many people [8].

The most common definition of medical necessity is, “health care services that a physician, exercising prudent clinical judgment, would provide to a patient for the purpose of preventing, evaluating, diagnosing or treating an illness, injury, disease or its symptoms, and that are in accordance with generally accepted standards of medical practice” [7]. Generally accepted standards of medical practice are those that are evidence-based and published in peer-reviewed medical literature as well as Physician Specialty Society recommendations [7]. Gender dysphoria can lead to symptoms of clinical depression and the ultimate result is that 41% of trans persons have attempted suicide compared to <2% of the general population in the US [15]. Decades of both clinical experience and medical research have established that HT and/or surgery are effective in treating the symptoms of gender dysphoria and essential to achieving well-being for trans persons [8].

Nonetheless, there is a stigma attached to gender nonconformity in many societies around the world. Such stigma can lead to prejudice and discrimination. For those reasons, many trans persons are reluctant to disclose their gender identity, even in healthcare settings, because of anxiety over the potential negative consequences. The National Transgender Discrimination Survey published in 2010 found that 19% of respondents had been refused care due to their gender identity [15]. The survey also found that 28% of trans people had been verbally harassed and 2% had been physically assaulted while attempting to receive medical care [15]. Negative interactions in health care settings can make an already vulnerable experience unbearable, leading trans persons to delay or avoid necessary services putting their overall health at risk. For example, in order to avoid such interactions the patient might decide to obtain medicines and treatments from nontraditional sources or to forgo care completely. In fact, the prevalence of unsupervised hormone use in urban transgender populations reportedly ranges from 29% to 63%, a behavior that poses significant health risks [16]. Furthermore, even if trans persons are willing to disclose their gender identity, mechanisms to identify and monitor such patients are not in place.

Structural barriers

The structural barriers to care for trans persons are diverse. Based on the 2010 National Transgender Discrimination Survey, a guideline for hospital policies to overcome structural barriers was published by a coalition of civil rights advocacy groups [17]. Some of the barriers are relatively easy to address such as restroom access. Trans persons may be uncomfortable with public restrooms that are restricted by gender and the availability of a private, unisex restroom contributes to a trans affirming environment. Similarly, trans persons should be given the option of having a private inpatient room assignment. If a private room is unavailable or the patient prefers to share a room they should be assigned to a room with a roommate of the same gender identity. In this case, however, it is necessary for the admissions office to ascertain the patient’s gender identity usually based on admission and/or registration records, which may not be simple.

The great majority of healthcare IT solutions including electronic health records (EHRs), billing/coding systems, and laboratory information systems (LISs) have implemented a binary male/female identification system. While it accurately captures most of the patient population, this structure impedes the collection of accurate medical information in gender nonconforming populations. In 2010 the Institute of Medicine (IOM) recommended that data on gender identity be collected in EHRs as one component of meaningful use objectives [1]. In response, the WPATH executive committee convened an EHR working group in 2011 comprised of expert clinicians and medical information technology specialists to make recommendations for the development and use of EHR systems with respect to trans patients [18].

The working group recommended that demographic variables of an EHR should include preferred name, gender identity, and pronoun preference as identified by patients [18]. Trans persons often have preferred names and/or pronouns that differ from their legal documents, their health insurance policies, and/or physical sex assignment. Failure to be identified by a preferred name or pronoun can cause discomfort leading to a poor rapport with providers and impacting quality of care [15,19]. Additionally, identification by a name or pronoun that is not consistent with sex (i.e. physical appearance) can potentially target the patient for prejudice and harassment from staff and/or other patients. Equally, EHRs should maintain an accurate record of the patient's medical transition history and current anatomy [18]. For example, a female-to-male (FTM) trans person may outwardly appear to be male and prefer a male pronoun. However, the patient may retain female organs and still require screening for breast, ovarian, and uterine malignancies. Similarly, a male-to-female (MTF) trans person may outwardly appear female and prefer a female pronoun, but still require screening for prostate cancer. In current systems, even if gender identity is disclosed, providers may be completely unaware that trans persons retain any organs of their assigned sex. Alternatively, even if they are aware of it, ordering a pap smear on a patient registered as male or a prostatic ultrasound on a patient registered as female is next to impossible. Therefore, organ systems and the related procedures must be uncoupled from gender identification in order for an EHR to be an effective tool in the care of a trans patient.

Many laboratory tests are linked to gender in LISs as well. The primary reason for this is that many clinical laboratory tests are reported to the clinician with reference ranges that are gender-specific. For example, a testosterone measurement in a patient identified as female in the LIS will display with a reference range for a healthy female. However, for a MTF trans person, it would be more useful for the clinician who is monitoring their HT levels to know the reference range for a healthy male since that is the target range for the therapy [8,14]. Additionally, it is not only the sex hormones (e.g. testosterone and estrogen) that are linked to gender. Of the tests recommended for routine monitoring by The Endocrine Society guidelines for the care of trans persons, alanine aminotransferase (ALT; a liver enzyme), creatinine (a component of the renal panel), components of the CBC (red blood cell count [RBC], iron, and hemoglobin), as well as prolactin, estrogen, and testosterone (all hormones) have different reported reference intervals for male and female [14]. Whether it is more appropriate to report the reference interval of the assigned sex or the identified gender for a trans patient is still unclear. More research is needed to determine what ranges are normal for a patient on HT, but more work is also needed to develop LISs that will allow the flexibility to report the appropriate reference intervals.

Financial barriers

The user-driven recommendations of the WPATH working group will, hopefully, better inform health information technology research and EHR vendors on the unique needs of trans patients [18]. However, improvements in EHRs and LISs will be insufficient to overcome some obstacles to care particularly with regard to screening of assigned sex organ systems in patients registered under their identified gender. In these cases, care will still be hindered by billing/coding systems and insurance issues.

Another staggering finding of the National Transgender Discrimination Survey was that 48% of trans persons had delayed seeking medical care when they were sick or injured because they were unable to afford it [15]. One contributory factor is a disproportionate level of unemployment within the trans community. Approximately 14% of the trans population is unemployed, nearly twice the national average [15]. Therefore, the option of employer-based coverage is limited in this population [7]. In the individual insurance market, trans identity has long been considered a preexisting condition disqualifying trans persons for coverage.

However, with the passage of the Patient Protection and Affordable Care Act discrimination based on gender identity is now prohibited. However, even if a policy is granted, "transition-related care" is usually excluded and it is all too easy for insurance companies to encompass even routine preventative services under the "transition-related" umbrella [7,15].

Despite the exclusion of transition-related care, most trans persons have accessed or sought this type of care at some point [15]. Counseling and HT are more readily available and are highly utilized but the high costs of surgery render these medically necessary procedures inaccessible to most trans persons. While a majority of trans persons report wanting to pursue gender reassignment surgery in the future, it is impossible to determine how many would desire and/or utilize the surgical procedures if the financial resources were available [15].

It seems logical that routine care and screening of retained assigned sex organs would not be excluded as transition-related. Nonetheless, billing and coding systems often make access to this type of care so complex that many trans persons will delay or avoid this necessary treatment. As with EHRs, billing and coding systems within both healthcare facilities as well as insurance providers have linked gender to organ systems and the associated procedures [18]. As a result, even if a healthcare provider is able to order and perform the procedure it will not be covered by the insurance providers because of incompatibility with the identified gender [7,20].

Providers: education and evidence

Frank discrimination and health care environments that are ill adapted to the unique needs of trans patients continue to contribute to limiting access. Cultural sensitivity training for healthcare providers has been shown to have some efficacy in a number of settings [21]. However, recent recommendations have suggested implementing protocols for interaction with special populations including trans persons [17]. Such protocols would complement cultural training and aid healthcare providers and staff in comfortably interacting with trans patients, ensuring that they are treated with professionalism, courtesy, and respect.

With the increasing visibility of the trans population, perhaps a more impressive barrier to care is a global lack of knowledge and information on the part of healthcare providers [2,20]. Transgender patients have unique healthcare concerns that include a four-fold greater risk of contracting HIV than the general population, a much higher incidence of alcohol and drug abuse, and suicide/suicide attempt rates as high as 40% [1,22]. However, data and resources for transgender health are substantially more deficient than with gay and lesbian health. International professional organizations, namely WPATH and The Endocrine Society, have identified the need for formal guidelines for the care of trans persons, which underscores the lack of information and resources in this area. In the last five years, both organizations have published standards of care based on recommendations of expert panels [8,14]. Nonetheless, physicians, nurses, and other healthcare providers receive little to no formal training to aid them in adequately caring for trans patients [2,4,5,23,24].

The trans community, a number of professional organizations including WPATH, and experienced specialist providers have recommended that HT is best undertaken in the context of comprehensive primary care [8,14,25,26]. The Endocrine Society guidelines for the care of transgender patients provide specific guidance regarding the types of hormones and suggested dosing to maintain levels within physiologic ranges for a patient's desired gender expression [14]. With the guidelines that are available, primary care providers should be able to manage HT. In fact, many of the tasks related to management of comorbidities associated with long-term hormone use fall more within the scope of primary care. However, moving treatment of trans patients into the mainstream has been a challenge, primarily due to barriers perceived by providers [26].

An exploratory qualitative study published in 2012 found that physicians perceive significant barriers when providing healthcare services to trans patients [2]. Many of the barriers cited had been previously identified by the trans community, including the low availability of trans healthcare services, the inaccessibility of resources and appropriate referrals, and inadequate medical knowledge and training. Additionally, the uncertainty of both the legitimacy of HT as well as patient satisfaction often complicates the clinical management of trans patients [2,26]. In the 2012 study, respondent physicians with experience in gender transitioning treatments expressed concern that patients may be unsatisfied with results or, worse, altogether regret their decision to undergo treatment [2]. These concerns highlight the lack of information on long-term outcomes and potential complications of gender transitioning treatments.

Limited access to reliable sources of information also impedes physicians in providing care to trans patients. In a 2010 article in *Advances in Nursing Science*, Eliason and colleagues described a “silence” regarding LGBT health [23]. They reviewed the top 10 nursing journals from 2005 to 2009 and found only eight articles (out of nearly 5000) that focused on LGBT issues. Seven of the journals contained no articles at all on this topic. The literature available on the health and health care issues specific to the trans community is even more limited and, often, difficult to find. The Endocrine Society guidelines for the care of transgender patients were published in 2009 [14]. Subsequently, the WPATH standards have set out guidelines for diagnostic assessment, psychotherapy, real-life experience, HT, and surgical therapy [8,27].

Evidence based care

The guidelines for the care of transgender patients published by The Endocrine Society state that, while HT is a necessary treatment for individuals with gender dysphoria to alleviate their mental suffering, it confers the same risks associated with sex hormone replacement therapy in biological males and females [14]. These risks are then often worsened by inadvertent or intentional use of either supraphysiologic or inadequate doses of sex hormones. Some of the key health issues related to HT include thromboembolic disease, liver dysfunction, and cardiovascular disease. The Endocrine Society guidelines recommend that medical conditions that can be exacerbated by HT be evaluated and addressed prior to initiation of treatment. In terms of long-term care and prevention of adverse outcomes, clinical and laboratory monitoring is recommended every three months during the first year of treatment and semi-annually thereafter [14].

The top causes of death among adult men in the U.S. are heart disease, stroke, and cancer, according to the Centers for Disease Control and Prevention [28]. All of these conditions can be worsened by HT in both MTF and FTM trans patients. For MTFs, one of the desired consequences of HT is decreased muscle mass and an increase/redistribution of body habitus [29]. Increased body weight can lead to hypertension and other risk factors for both heart disease and stroke. However, HT can potentially lead to improved lipid profiles in MTF patients [30]. Consequently, trans patients should be evaluated clinically for cardiovascular risk factors [14]. This type of screening and assessment would ideally fall under the purview of primary care [8]. However, primary care providers remain apprehensive about management of trans persons due to the added factor of HT. It is imperative that primary care providers receive training and information regarding appropriate care of trans patients so that the overall health of these patients can be better managed.

Similarly, MTF persons are known to be at higher risk of breast cancer as a result of HT and should, therefore, follow the screening guidelines recommended for biological women [14]. Furthermore, they will also require screening for prostatic disease and prostate cancer [14]. FTM persons will need screening for breast, ovarian, uterine, and cervical cancer if those organs are retained [14]. In addition to the structural barriers to this type of preventative care and screening already

discussed, providers need to be aware of these guidelines. Moreover, trans persons may be uncomfortable discussing organ systems related to their sex, which are not aligned with their gender identity. Providers also need training to be able to approach this type of screening in a sensitive way.

Routine laboratory monitoring of trans patients can be challenging because many of the measurands that are recommended for testing have gender-specific reference intervals. Analytes like liver enzymes, lipid profiles, and cardiac markers are all reported to the clinician with reference intervals indicating the upper and lower limits of the population based on the indicated sex of the patient. However, it is unclear which reference intervals are most appropriate for a trans patient (sex at birth or identified gender) or whether new reference intervals need to be developed to adequately and safely monitor trans patients on HT.

A recent retrospective study found that many of the analytes recommended for routine monitoring in trans persons were not measured or followed with any regularity [30]. This may be partially attributable to a lack of provider knowledge and experience. However, it is equally likely that it may be due to the financial burden. Laboratory monitoring of estrogen or testosterone is necessary in these individuals to ensure that cross-sex hormone levels are maintained in the normal physiological range for the desired gender as supraphysiologic doses are more likely to lead to adverse events. However, these measurements are likely to be considered transition-related and, therefore, not covered by insurance providers.

The study also found consistent changes in analyte levels with HT, which did not fit neatly into either the male or female reference ranges [30]. However, these changes did not seem to be indicative of any adverse events and were more likely a part of the desired physiological changes induced by the therapy. However, without knowing that these differences are to be expected, exacerbated by the possibility that the gender identity of the patient is unknown, results that are outside the reported reference range can lead to unnecessary follow-up and treatment. This was the first study to investigate clinical laboratory monitoring of trans patients and the data suggests that, especially for laboratories that service large trans communities, new reference ranges specifically for trans patients on HT should be empirically determined in order to safely monitor these patients [30].

The Clinical Laboratory Standards Institute's (CLSI) guideline (C28-A3) for establishing reference ranges recommends using non-parametric methods (2.5th–97.5th percentiles) based on values from 120 “healthy” individuals [31]. For FDA approved tests, manufacturers are required to include reference ranges and C28-A3 allows clinical laboratories to test only 20 reference samples with $\leq 10\%$ of values falling outside the range provided in order to validate that reference interval. Identifying “healthy” trans patients for reference range validation is often not feasible because approximately 50% of trans persons will never seek preventative care [15]. Similarly, the difficulty in identifying reference samples has been a bane for pediatric laboratory medicine, and since the majority of pediatric testing is focused on hospitalized patients it is almost impossible to identify reference samples from “healthy” children [32]. Further complicating matters is the understanding that normal ranges in children will differ by age groups [32]. Similarly, normal ranges in trans persons may differ based on the duration, dose, and/or delivery method of HT. To date, there has been only one study published regarding clinical laboratory reference ranges in trans patients [30]. The lack of information in this area is obtrusive and further study will be necessary to definitively identify reference ranges that are appropriate and useful in this population.

Conclusion

The optimal provision of healthcare and prevention services to sexual and gender minorities requires providers to be sensitive to historical stigmatization and to be informed about continued barriers to care and the differential prevalence of specific risk factors and health conditions in these populations. Potential solutions to improve access to healthcare

for trans patients must address the four main barriers to care discussed in this review.

Historical stigmatization as well as many negative personal experiences in healthcare settings fosters a reluctance to disclose gender identity. Improving the overall healthcare experience for trans patients will be critical to overcoming this barrier. Great strides have been made towards removing the stigmatization of transgenderism as a “disorder” with the adoption of the DSM-5 and the new chapter on gender dysphoria [8,12]. Additionally, publication of guidelines for care by both WPATH and The Endocrine Society has further lessened the stigma by encouraging redistribution of trans care from secondary to primary care settings [8,14]. However, improvement of the overall experience is heavily dependent on finding solutions to the barriers resulting from the three remaining themes.

The infrastructure of healthcare needs to change in order to better serve the trans population. Flexibility in EHRs, LISs, and other IT systems to allow for better accounting of assigned sex, identified gender, preferred names/pronouns, and transition related medical history will be critical. However, in addition to expanding the functions of IT systems to better manage trans patients, facilities could also use some improvement. A simple addition of a unisex restroom would put many a trans patient more at ease. Lastly, training and protocols that guide frontline staff to better collect information on gender identity and transition history in a sensitive manner will improve the overall healthcare experience for these patients.

Many trans organizations are lauding the passage of the Patient Protection and Affordable Care Act as a major step forward for trans healthcare from a financial standpoint. Trans identity can no longer be considered a “pre-existing” condition and policies cannot be denied on the basis of gender identity. Nonetheless, there is still a long way to go as “transition-related” care can still be excluded.

In terms of provider barriers, increased dissemination of current sources of information (i.e. guidelines), incorporation of trans healthcare issues into medical curricula, and better collaboration with knowledgeable colleagues would clearly increase provider knowledge, skills, and confidence in dealing with trans patients. However, the evidence driving many of the guidelines is still lacking. More research and investigation into the long-term outcomes of HT is necessary to improve the overall healthcare delivered to the trans population.

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